Quantifying disability: data, methods and results

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Conventional methods for collecting, analysing and disseminating data and information on disability in populations have relied on cross-sectional censuses and surveys which measure prevalence in a given period. While this may be relevant for defining the extent and demographic pattern of disabilities in a population, and thus indicating the need for rehabilitative services, prevention *requires detailed information on the underlying diseases and injuries that cause disabilities. The Global Burden of Disease methodology described in this paper provides a mechanism for quantifying the health consequences of the years of life lived with disabilities by first estimating the age-sex-specific incidence rates of underlying conditions, and then mapping these to a single disability index which collectively reflects the probability of progressing to a disability, the duration of life lived with the disability, and the approximate severity of the disability in terms of activity restriction. Detailed estimates of the number of disability-adjusted life years (DALYs) lived are provided in this paper, for eight geographical regions. The results should be useful to those concerned with planning health services for the disabled and, more particularly, with determining policies to prevent the underlying conditions which give rise to serious disabling sequelae.*

Introduction

This paper is one of four in this issue of the *Bulletin of the World Health Organization* on the Global Burden of Disease study (*1–3*). Through the study, a new measure, the disability-adjusted life year (DALY), was developed and applied to estimating the burden of disease due to more than 100 causes, for five age groups and the two sexes in eight regions of the world. The conceptual underpinnings of the strategy used to measure the time lived with a disability in a manner that can be meaningfully compared with the time lost due to premature mortality have been described (*1*). This article focuses on the methods, sources and results for the measurement of time lived with a disability. DALYs require for their computation extensive age- and sex-specific information for regions on the incidence of disease, the proportion of disease incidence leading to a disabling outcome, the average age of disability onset, the duration of disability, and the distribution of disability across the six classes of disability severity.

For some regions, there are minimal data on the epidemiology of important health problems. Few community studies, for example, are available on heart disease in sub-Saharan Africa. Knowledge of the disabling sequelae even of well-studied diseases is missing for large parts of the developing and surprisingly the industrialized worlds. Nevertheless, choices between competing health priorities are made every day by decision-makers in the public and private sectors. These choices reflect their implicit understanding of the epidemiological profile as well as opportunities for intervention. The philosophy of the Global Burden of Disease study is that assumptions about the burden of disease should be made explicit. In other words, it is preferable to make an informed estimate of disability flowing from a particular condition than to have no estimate at all. No estimate often leads to the tacit assumption that there is no problem. Perhaps, the continued neglect of primary and secondary prevention and rehabilitation of disability is related to the lack of data on its magnitude that is comparable with life lost due to premature mortality.

Materials and methods

Study design

To calculate DALYs, detailed estimates of the age- and sex-specific epidemiology of each disease are required. Table 1 illustrates the worksheet developed for each disease for each of the eight regions; the sample provides results for cataract-related blindness in sub-Saharan Africa. Estimates of disease incidence, proportion becoming disabled, average age of

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Table 1: **Sample worksheet for estimating years of life lived with a disability (blindness due to cataract) in sub-Saharan Africa, disability only, 1990**

Sex and age group (years)	Incidence (cases)	Age of onset (years)	Duration (years)	Disability weight	YLD incidence age[a]	YLD age lived[b]	Incidence (per 1000)	Prevalence (per 1000)	Population (x 1000)	Prevalence (cases)	YLD prevalence[c]
Male											
0–4	1 899	0.5	23.28	0.583	18 448	1 791	0.04	0.08	47 484	3 989	355
5–14	0	0	0	0	0	8 718	0.00	0.16	70 258	11 031	7 097
15–44	5 188	35	13.42	0.583	42 882	42 286	0.05	0.76	103 764	79 276	63 461
45–59	74 124	55	8.48	0.583	292 583	196 725	3.65	23.40	20 308	475 288	267 288
60+	111 805	70	4.89	0.583	192 771	297 164	10.64	90.46	10 508	950 596	372 690
Total	193 017				546 684	546 684			252 322	1 520 179	710 891
Female											
0–4	1 881	0.5	20.37	0.583	15 810	1 774	0.04	0.09	47 030	3 998	356
5–14	0	0	0	0	0	8 634	0.00	0.16	69 818	11 031	7 097
15–44	6 375	35	13.46	0.583	52 808	47 610	0.06	0.78	106 257	82 349	65 922
45–59	78 073	55	8.86	0.583	318 972	208 816	3.53	22.35	22 117	494 381	278 026
60+	110 751	70	5.02	0.583	195 347	316 104	8.70	77.69	12 730	988 994	387 744
Total	197 081				582 938	582 938			257 952	1 580 753	739 145

[a] DALYs attributed to the age of onset of a disability.
[b] DALYs attributed to the age at which a disability would be lived.
[c] DALYs calculated using prevalence of a disability times a duration of 1 year.

onset of the disability, duration of the disability, and distribution of disabilities across the six classes of severity are required. In addition, information on prevalence, remission, and case fatality were used in checking for internal consistency and calculating the duration and mortality. Valid community-based epidemiological studies for information on these estimates do not exist for many of the variables in many regions. To both identify all useful sources and supplement empirical data with informed judgment, we used an iterative process that was implemented over a period of 9 months. The following eight steps are a summary of the actual mechanism used to generate estimates for each disease.

(1) More than 100 conditions were chosen to be included in the Global Burden of Disease study. The set which is organized in a tree structure begins with three large groups: communicable, maternal and perinatal; noncommunicable; and injuries. Group I (communicable, maternal and perinatal) are all causes that decline dramatically with the epidemiological transition (*4, 5*). The remaining causes have been divided into noncommunicable diseases and injuries because injuries appear to be largely unrelated to the total level of mortality and noncommunicable disease patterns (*6*). This basic structure was first developed in the World Bank study on adult health (*5*) and has been modified by adding conditions that were known to be large causes of mortality and significant contributors to disability, or for which significant resources are spent in the health sector.

(2) Disease experts, or groups of experts in some cases, were identified for each of the more than 100 conditions in the Global Burden of Disease study. Study participants were drawn from the World Health Organization, the International Agency for Research on Cancer, the World Bank, the U.S. Centers for Disease Control, and academic institutions in several countries including China, France, India, New Zealand, Sri Lanka, United Kingdom and USA.

(3) First-round estimates were made by experts on the basis of published and unpublished studies of disease and disability incidence, remission, case fatality, prevalence, and the distribution by severity class of the disability. Where no data for a region were available, experts were encouraged to make informed estimates. Frequently, age patterns of incidence of remission were based on regions thought to have similar epidemiological profiles. In the worst case, when no information was available, all rates would be imputed from other regions.

(4) These estimates were reviewed critically by the authors. Internal consistency between incidence, remission, case-fatality rates, duration, and prevalence estimates was ascertained using the Harvard incidence-prevalence model described below. These checks identified major inconsistencies with many estimates. Disease experts then revised their estimates, in consultation with us, to make them internally consistent.

(5) Revised estimates were used to produce the Version 1 results. These estimates were extensively reviewed by a large group of international health

experts at a WHO meeting on 8–11 December 1992. Disease experts subsequently revised their estimates, taking the discussions at this conference into account. These revisions were subjected again to internal consistency validation and then used to generate Version 2 results.

(6) The mapping from disease to disability and the distribution of disabling sequelae across the six severity classes was independently reviewed. A group of public health practitioners, meeting in Atlanta on 15 March 1993, were charged with modifying these distributions as required to make each disability class homogeneous with respect to severity.

(7) Version 3 results, based on these revisions of the mapping of disease to disabling sequelae by class, were published recently (7).

(8) Selected disease experts have subsequently revised their estimates based on wider critical review and recently collected data, and these modifications have been incorporated into the Version 4 results presented here.

From prevalence to incidence and back

Three clear needs were appreciated early in the exercise.

(1) Results of studies have been reported using different indicators. Prevalence results differed in the age groups used and the indicators used such as point, period or lifetime cumulative prevalence. A simple method to convert between measures was needed to facilitate comparisons of study results.

(2) When estimates of incidence, duration and prevalence were made, internal consistency between the two had to be established.

(3) Data on prevalence were available frequently, but none on incidence.

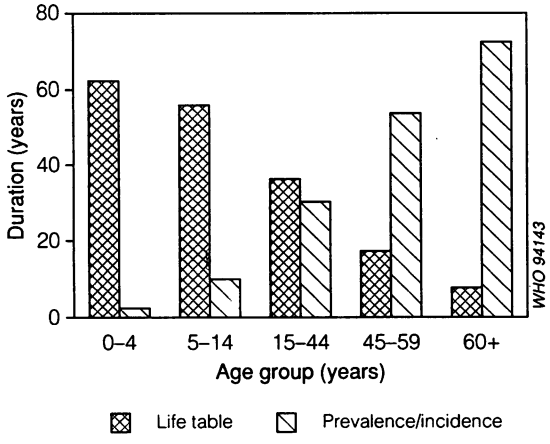
Estimates of incidence consistent with observed prevalence had to be developed.

The relationship between epidemiological variables is not simple. The oft-cited relationship:

$$P = ID$$

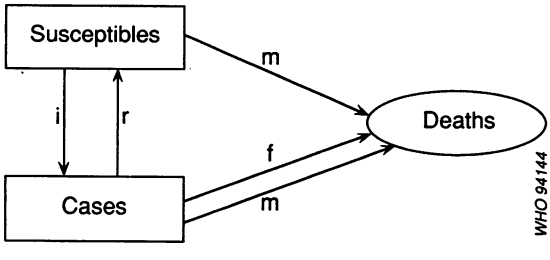
(where P is prevalence, I is incidence and D is duration) is an oversimplification. It holds true for the population on average only if the incidence has been constant over time. For calculating DALYs, we need to know the average duration of a disability at different ages of onset. When the equality $P = ID$ is extended to determining the duration by age of onset, it no longer works under most circumstances. Fig. 1 shows the average duration estimated using prevalence, divided by the incidence within an age group and the true duration for the same age group for a disease with a constant incidence of 1 per 1000 across all ages and no case-fatality rate. With rising age, true duration is lower because of increasing general mortality and thus declining life expectancy, whereas duration estimated by age-specific prevalence divided by incidence is increasing because of the accumulation of prevalence cases.

Fig. 1. **Comparison of estimated durations: prevalence/incidence and life-table methods.**



In order to address these needs, we developed a model formalizing the relationship between incidence, remission, case fatality, and prevalence. Fig. 2 illustrates the basic relationships. Susceptibles in the population can get a disease or disability at rate i and can die at a general mortality rate m. Cases of disease or disability can remit at rate r, die from general causes at the same rate as the susceptibles m, and die from cause-specific mortality at rate f. If these rates can be approximated as constant over a short interval such as a year, we can define a set of linear differential equations that characterize movement between the three states shown. Using matrix algebra, this is a simple problem to solve. In fact, a general eigenvector/eigenvalue solution can be conveniently written in a spreadsheet such as Lotus 123. We then follow a cohort from birth onwards exposed

Fig. 2. **Schema for the Harvard incidence-prevalence model.**



to a set of age-specific incidence, remission, case fatality, and general mortality risks using a life-table approach. For each year in the life-table, a new solution is calculated for the set of differential equations and this solution is used to calculate the number of susceptibles, cases and deaths for the beginning of the next year. This process is repeated until a competing-risks life-table has been fully constructed until age 85 years.

More specifically, the model input is a set of instantaneous incidence, remission, and cause-specific mortality risks for the age groups 0–4, 5–14, 15–44, 45–59 and 60+ years. Within each age group, we have made the simplifying assumption that the various instantaneous risks are constant. General mortality rates for the eight regions for males and females are built into the programme and are selected through a menu. The output of the model (shown in Table 2) provides prevalence rates and numbers by age, deaths attributable to that condition, incidence rates, and duration by age of onset. The data in the Table are for asthma in Indian women.

This model, named the Harvard incidence prevalence model, now in its sixth revision has been used primarily for three purposes. First, when prevalence is known and reasonable assumptions about remission and case fatality can be made, the model can be used iteratively to define incidence and duration by age. Second, when incidence is known we can simply estimate the expected prevalence. This is useful in establishing internal consistency between the estimates of incidence and prevalence. Third, for diseases such as diabetes where there is a relative risk from all causes or a group of important causes, like cardiovascular diseases, attributable deaths rather than directly coded cause-specific mortality can be easily estimated.

Table 2: **Harvard disease model output for asthma for females in India**

Inputs to model	Instantaneous rates		
Age groups (years)	Incidence	Remission	Cause-specific mortality
0–4	0.00675	0.430	0.00325
5–14	0.00377	0.440	0.00368
15–44	0.00155	0.335	0.00580
45–59	0.00223	0.138	0.00700
60+	0.00259	0.268	0.01400

Output from model			
Prevalence rate (per 1000)	Expected duration (years)	Annual incidence rate (per 1000)	Annual cause-specific mortality rate
8.984	1.92	6.69	0.029
9.583	2.21	3.73	0.035
4.914	3.55	1.54	0.029
10.761	3.77	2.21	0.075
10.125	2.33	2.56	0.142
Population (x 1000)	Prevalence	Annual incidence	Annual cause-specific deaths
56 679	509 228	378 966	1 655
95 263	912 931	355 445	3 360
183 242	900 483	281 772	5 223
46 005	495 075	101 583	3 466
28 924	292 863	74 029	4 100

Mapping disease to disability and adjusting for treatment

A major obstacle to linking public health studies on particular diseases with research on disability has been the absence of a probability map extending from disease to impairments and disabilities. While on paper, arrows may be drawn from disease all the way to handicap, even those who work on disability can rarely provide concrete information on the probability that someone with a particular disease will go on to suffer disabilities of particular severities. For the Global Burden of Disease (GBD) study, such a mapping from disease through impairment to disability was required. As described in the section on study design, this map was developed in an iterative fashion based on inputs from disease experts and then independently reviewed.

Table 3 provides the distribution, by severity class, of disabilities stemming from selected diseases in the GBD list for one region (Latin America and the Caribbean). The full detail is too extensive to present here but is available, on request, to those who are interested. Some diseases may cause several disabilities and consequently have more than one entry in the Table. The Table provides the proportion of disease incidence cases that go on to develop a disability, which varies by region and age group, and the distribution of disabling sequelae by class. For some conditions, the percentage becoming disabled is better interpreted as the proportion of time the individuals with this condition are disabled, such as for bipolar affective (manic-depressive) disease or asthma. The proportion going on to develop a disability is also a function of the definition of incidence; a restricted definition of incidence means a higher proportion will go on to develop a disability, a loose definition means a lower proportion will develop a disability. The definition of incidence used in the study often depends on the definitions used in extant datasets. For example, the data on motor vehicle accidents in Mexico, based on police records, refer only to those injuries that lead to hospitaliza-

Table 3: **An estimated proportion of incident cases developing a disability and the distribution of these disabilities by severity class for a few illustrative conditions in LAC males**

Disease/injury	Age group (years)	Proportion of incident cases developing a disability	% Distribution of those developing a disability by severity class[a]					
			I	II	III	IV	V	VI
			0.096[b]	0.220[b]	0.400[b]	0.600[b]	0.810[b]	0.920[b]
Communicable, maternal and perinatal:								
Meningitis								
Acute	0–4	100	0	0	0	50	35	15
	5–14	100	0	0	0	50	35	15
	15–44	100	0	0	0	50	35	15
	45–59	100	0	0	0	50	35	15
	60+	100	0	0	0	50	35	15
Retardation	0–4	8	0	50	50	0	0	0
	5–14	8	0	50	50	0	0	0
	15–44	8	0	50	50	0	0	0
	45–59	8	0	50	50	0	0	0
	60+	8	0	50	50	0	0	0
Deafness	0–4	2	0	0	100	0	0	0
	5–14	2	0	0	100	0	0	0
	15–44	2	0	0	100	0	0	0
	45–59	2	0	0	100	0	0	0
	60+	2	0	0	100	0	0	0
Noncommunicable:								
Lung cancer:								
Terminal	0–4	100				40	30	30
	5–14	100				40	30	30
	15–44	100				40	30	30
	45–59	100				40	30	30
	60+	100				40	30	30
Preterminal	0–4	50	100					
	5–14	50	100					
	15–44	50	100					
	45–59	50	100					
	60+	50	100					
Psychoses	0–4	100			60	25	15	
	5–14	100			60	25	15	
	15–44	100			60	25	15	
	45–59	100			60	25	15	
	60+	100			60	25	15	
Cerebrovascular	0–4	100	35	30	15	10	5	5
	5–14	100	35	30	15	10	5	5
	15–44	100	35	30	15	10	5	5
	45–59	100	35	30	15	10	5	5
	60+	100	35	30	15	10	5	5
Periodontal disease	0–4	10	100					
	5–14	10	100					
	15–44	10	100					
	45–59	10	100					
	60+	10	100					
Injuries:								
Motor vehicle accidents	0–4	10		30	30	30	10	
	5–14	10		30	30	30	10	
	15–44	10		30	30	30	10	
	45–59	10		30	30	30	10	
	60+	10		30	30	30	10	
Falls	0–4	50		50	40	10		
	5–14	50		50	40	10		
	15–44	50		50	40	10		
	45–59	50		50	40	10		
	60+	80			40	40	30	

[a] Note distributions across the six classes of disability sum to 100 percent.
[b] Weight for time spent in each disability class.

tion whereas in other countries they refer to all motor vehicle accidents in which a vehicle is damaged.

The mapping in Table 3 is preliminary; undoubtedly, it will be substantially revised as more attention is directed to the disabling sequelae of disease and definitions of incidence are altered. More detail on a the map and its empirical basis will be provided in a forthcoming book on the global burden of disease and injury (*8*). Another important improvement to previous approaches to assessing disability is the inclusion of short-term consequences of disease such as diarrhoeal diseases which have not traditionally been considered as a cause of disability although, by virtue of the volume of cases, they represent a significant proportion of the overall disease burden.

A final issue in the calculation of DALYs due to disability must be addressed: the effects of treatment or rehabilitation on disability. The objective of measuring DALYs is to quantify the current burden of disease, taking into account current activities including preventive and curative health care. Medical intervention can affect disability in four ways: changing the disease incidence, the probability of developing a disabling sequelae, the duration of disability, and the severity of disability. The first three treatment effects are already captured in the calculation of DALYs as described here and by Murray (*1*). When the proportion progressing to a disability is less than 100%, an adjustment is made to the disability weight itself. Changes in the severity of disability or the distribution of disabilities across the six classes owing to treatment has not so far been captured. In the case of certain disabling sequelae, such as those due to angina, cerebrovascular disease, conditions causing near-blindness, schizophrenia and others, interventions can reduce their severity. We have tried to capture this treatment effect by introducing a series of adjustments to the disability weight for each region and age-sex group, reflecting the likely impact of treatment on the distribution of disabilities across the six classes.

Results

The overall magnitude of disability by cause group and its distribution by age and region are summarized in Table 4, in which YLD refers to DALYs due to years of life lived with a disability. The Established Market Economies (EME) and the Former Socialist Economies of Europe (FSE) together account for only 15% of the global burden of disability (85% is in the developing world). However, as noted earlier (*1*), the proportion of total burden which is due to disability within EME and FSE is higher than in other regions. Owing to the combination of population size and high disease and injury rates, India and China together account for nearly 40% of the total years lived with a disability (YLD). Sub-Saharan Africa (SSA) and Other Asia and Islands (OAI) each account for about 15% of the global total.

Globally, only about one-quarter of the total disability burden is due to Group I conditions (communicable, maternal and perinatal), over 60% arise from noncommunicable diseases, and the remaining 13% from injuries and poisonings. The distribution of YLD, by broad causal group, across regions is particularly revealing. While Sub-Saharan Africa and India together account for almost half of the global total due to Group I conditions, our estimates suggest that in terms of numbers or years lived with a disability, there is more noncommunicable disability in India than in the Established Market Economies. As countries pass through the health transition, the distribution of YLD shifts away from Group I (which accounts for 44% in SSA but less than 10% in EME and FSE). The absolute and relative variation in the share of YLD due to Group III (injuries) is smaller—from 8% in EME to 18% in Latin America and the Caribbean.

The age pattern of disability DALYs by region, summarized in Table 4, suggests the need for much greater emphasis on health protection among young adults. Almost one-quarter of the global total of YLD are because of diseases and injuries occurring among young children, but significantly more (36%) arise from conditions incurred at ages 15–44. Another 15% or so is due to the incidence of disease and injury at older adult ages (45–59), and a comparable amount among the elderly (60 years and over). The largest number of YLD at ages 15–44, partly reflecting the population size, occurs in China and India. The contribution in other regions of the developing world is at least as great as in the EME region, emphasizing that, irrespective of the stage of the health transition, the prevention of disease and injury among young adults is a global priority.

Comparative rates of disability across the three groups of causes are summarized in Fig. 3 (females) and Fig. 4 (males). The top histogram presents the YLD rates per 1000 population per year by region for the age group 0–14 years, the middle histogram those for ages 15–59 years, and the bottom graph those aged 60 and above. While there will be some effect of differences in age structure within these three broad age groups, much of the effect of age structure across regions is controlled for in this disaggregation. Each bar for each region distinguishes YLD due to Group I, Group II and Group III. Although less so than for mortality, there is still more than a fivefold variation in the rates of disability in children aged 0–14 across regions. Disability

Table 4: **Percentage distribution of YLD[a] according to region, by broad cause group and age group, 1990**

Region	Cause group			All causes	Age group (years)					All ages
	I	II	III		0–4	5–14	15–44	45–59	60+	
EME	0.9	8.0	0.7	9.6	0.6	0.3	3.3	1.8	3.5	9.6
FSE	0.4	4.1	0.5	5.0	0.4	0.2	1.8	1.1	1.5	5.0
CHN	4.1	12.1	2.2	18.4	3.1	2.3	6.9	2.4	3.6	18.4
LAC	2.7	5.2	1.7	9.6	1.9	1.6	4.0	1.1	1.0	9.6
OAI	3.9	8.0	1.6	13.6	2.8	2.5	5.1	1.6	1.5	13.6
MEC	2.4	5.7	1.7	9.8	2.9	1.5	3.5	1.0	0.9	9.8
IND	5.3	12.2	2.2	19.7	6.1	2.6	6.5	2.3	2.1	19.7
SSA	6.3	6.1	2.0	14.4	5.0	2.4	5.0	1.2	0.8	14.4
All regions	26.0	61.4	12.6	100.0	22.8	13.4	36.2	12.6	15.0	100.0

[a] YLD are expressed as a percent of the global YLD.

in children arises from all three groups, although perinatal causes in Group I and congenital causes in Group II predominate. Disability rates in this age group are only slightly higher in males than in females. Below age 60, much of the difference between regions in YLD for females is due to Group I disability, particularly from sexually transmitted diseases and maternal causes.

The significantly larger contribution from Group III causes (injuries) in Latin American women at ages 15–59 is particularly notable, and consistent with the higher death rates from these causes compared to other regions. The main cause of Group II YLD among women at these ages is neuropsychiatric illness, for which the rates are very nearly equal in all regions. Among the elderly, noncommunicable diseases, as expected, are the main cause of YLD, with overall rates being similar in all developing regions, but markedly lower (about one-third less) in the developed world.

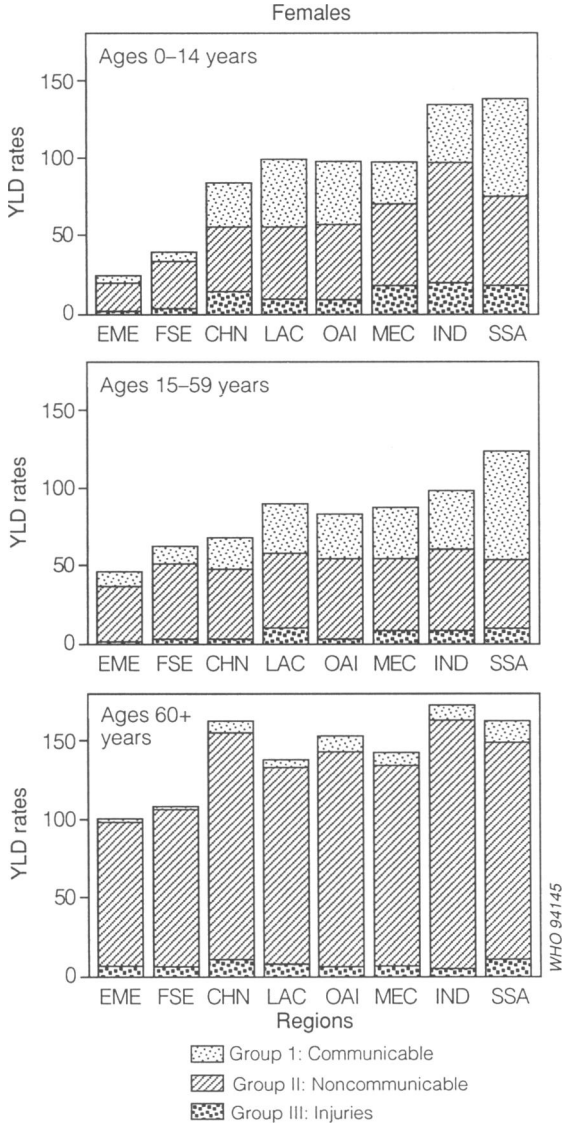
The matching histograms for males (Fig. 4) demonstrate the greater regional heterogeneity and variation across age groups than for females. The highest overall YLD rates are in SSA, followed by LAC, India and FSE. Group I is much more prominent as a cause of disability in adult women than in men. Group III is the greatest determinant of the difference between regions in male DALY rates. The extremely high Group III YLD rates in LAC, exceeding even those for SSA, are particularly notable. These estimates also confirm the significance of injuries as a major public health problem in Latin America, with the impact concentrated among young adult men.

Another representation of years of life lived with a disability (YLD) is based on the impact not at the age of onset, but at the age at which the disability would be lived. YLD attributed to the age lived can be considered as a form of projected future prevalence of YLD if current incidence rates were to hold constant. The age-sex-region specific rates using this alternative approach are given in Table 5. As expected, this perspective reveals higher rates of YLD lost at older ages because the disabling effect of disease and injury at earlier ages accumulates in a cohort. This effect is less apparent in EME and FSE, however, owing to a lower incidence of disabling conditions at younger ages compared with the developing world. The age pattern, however, is similar across all regions with monotonically rising rates, distinct from the J-shaped curve seen when analysing the rates by age of onset.

The sex ratio of YLD rates for the five age groups for each region is given in Table 6. In general, males have higher rates of disability. The notable exception is in the reproductive age group 15–44 years, where in most regions the rates are higher for women. Higher YLD rates in this age group reflect the substantial contribution of Group I causes in women. In older age groups, the situation is reversed although the excess in males is small except in FSE and EME.

More detail on the leading causes of YLD is given in Table 7, which shows within each age group and for each sex separately the percentage distribution of causes at the broad (Groups I, II and III) level of disaggregation and the next level down. Consider, first, the developed regions, EME and FSE. Congenital anomalies are by far the leading cause of YLD at younger ages (0–4 years), followed by perinatal conditions and injuries. Neuropsychiatric causes emerge as a major cause of disability at ages 5–14, with a further 20% of the burden in males and 13% in females because of injuries. This pattern is preserved for men aged 15–44 but diseases of the musculoskeletal system emerge as a major cause of disability in young women. Among adults aged 45–59, cardiovascular diseases and cancer each account for 15–20% of the disability burden with cardiovascular diseases rising to one-third of all

Fig. 3. **YLD rates for females within broad age ranges, by region, 1990 (rates/1000 population).**



YLD in both men and women at ages 60 and over. The Table also illustrates the importance of non-fatal conditions as contributors to the disease burden in these regions, with almost 10% of the YLD among women aged 45–59 being due to poor oral health.

A very different pattern of YLD is apparent for the developing regions. Infectious and parasitic diseases, nutritional and endocrine disorders, and injuries are the major contributors to YLD at ages 0–4 and again at ages 5–14 years. In young adult males, injuries (30.2%), neuropsychiatric disease (26%), and infectious and parasitic diseases (13.3%) are the most important causes of disability. In young females (15–44), disability is dominated by neuropsychiatric disease (21%), causes related to pregnancy (20%), and infectious and parasitic diseases (24.5%) including a large component due to sexually

Fig. 4. **YLD rates for males within broad age ranges, by region, 1990 (rates/1000 population).**

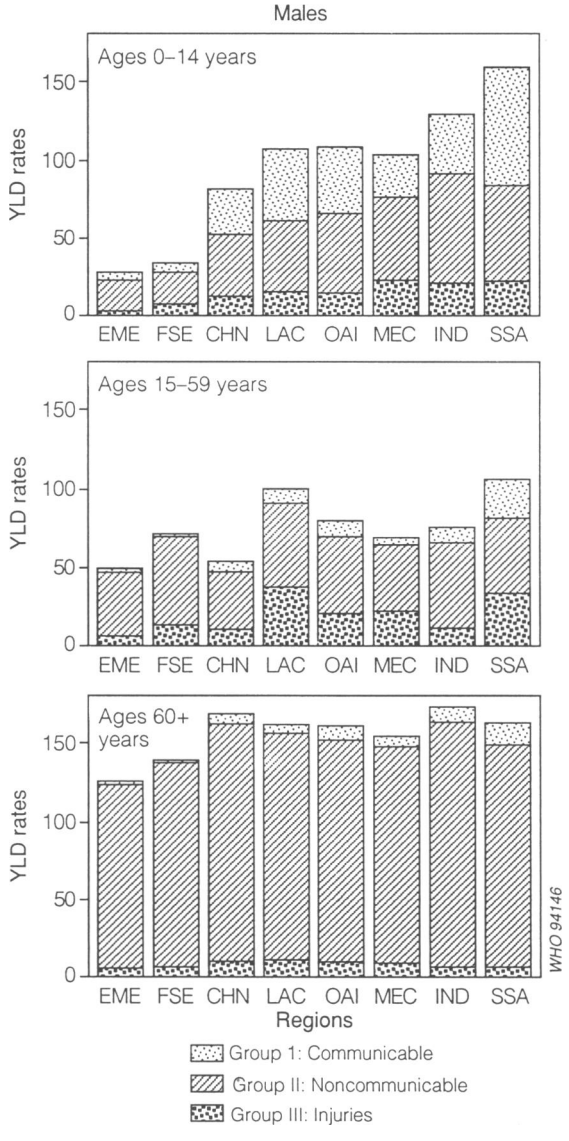


Table 5: **Rates of YLD age lived by region, sex and age group (per thousand population)**[a]

Region	Males in age group (years):					Females in age group (years):				
	0–4	5–14	15–44	45–59	60+	0–4	5–14	15–44	45–59	60+
EME	8	17	37	76	161	8	16	37	53	128
FSE	11	22	49	117	198	10	20	43	71	152
CHN	17	40	54	116	233	17	41	71	119	230
LAC	18	51	103	234	307	17	47	105	155	240
OAI	18	49	94	188	278	17	45	100	148	258
MEC	21	55	87	193	283	20	51	111	166	243
IND	31	65	101	175	256	34	68	136	158	237
SSA	66	78	158	257	289	64	71	173	205	252

[a] Please see text for a definition of YLD age lived.

transmitted diseases, especially pelvic inflammatory disease (PID). In older adult men and women the pattern of disability, by causes, shifts increasingly to cardiovascular diseases including ischaemic heart disease and stroke, chronic respiratory diseases, and other noncommunicable causes but neuropsychiatric disease, particularly the component due to dementia, remains a major factor.

Discussion

The estimates of the burden of disability represent an enormous effort on the part of nearly 100 disease experts to try and define the disabilities caused by most diseases and injuries. While the analysis provides an overall picture of disability by cause and is provocative in many details, we remain painfully aware of the limitations of the empirical database. Where no information is available, the results go beyond the database to speculate in a systematic fashion on the likely patterns of disability by cause, age and sex. Without this information, however, disability will continue to be underappreciated as a contributor to the burden of disease. The detailed review of each disease reveals the extraordinary dearth of data on disability from most diseases. We hope this study will stimulate interest in describing the burden of disability by cause, age, sex and location.

Table 6: **Ratio of male to female YLD rates**

Region	Age group (years):				
	0–4	5–14	15–44	45–59	60+
EME	1.04	1.21	0.94	1.43	1.26
FSE	1.06	1.23	1.07	1.53	1.26
CHN	0.92	1.04	0.70	1.11	1.03
LAC	1.07	1.09	1.04	1.41	1.17
OAI	1.04	1.17	0.89	1.17	1.05
MEC	1.03	1.13	0.70	1.29	1.09
IND	0.90	1.07	0,65	1.32	1.09
SSA	1.05	1.31	0.81	1.17	0.97

Most work on disability or impairment has been general in nature, measuring prevalence in the population of moderate and severe disability (*9–17*). These studies are important in their own right; but they do not identify the causes of disability and consequently have little influence on the allocation of health resources to specific interventions, except perhaps for rehabilitation services. The work reported here on disability linked to specific health problems and, by inference, specific health interventions should be seen as a complement and not a substitute to the efforts at defining and quantifying the general level of disability in the community.

Many of the estimates presented are uncertain. Indeed, for most we cannot even define statistically a 95% confidence interval. The degree of uncertainty also varies from disease to disease, across age groups, and between regions. How should uncertainty alter the way in which decision-makers analyse these results? According to economic theory, the response to uncertainty depends on whether utility as a function of the magnitude of a problem is linear or non-linear. The shape of the utility function depends on how risk-averse or risk-taking a society chooses to be. For most diseases, we cannot even speculate whether the utility or consequences for society as a function of the disease burden magnitude are likely to be linear or non-linear.

The issue can be simplified; decision-makers can treat very uncertain estimates with wide confidence intervals as the same as, or less or more important than an equal estimate with a narrow confidence interval. At the extreme, one can ignore the uncertain, an all too common response. For a few infectious diseases such as HIV, tuberculosis and some epidemic diseases, there is a potential for a secondary effect of increased transmission in the future if the true incidence is at the higher end of the confidence interval. In these cases, one might choose

Table 7: **Percentage distribution within each age group of YLD for developed and developing regions**

	Males in age group (years):						Females in age group (years):						Both sexes
	0–14	5–14	15–44	45–59	60+	All ages	0–4	5–14	15–44	45–59	60+	All ages	
Developed regions													
I. *Communicable, maternal and perinatal*	23.0	9.5	5.3	1.9	1.4	4.7	23.9	11.4	29.0	2.9	1.6	13.3	8.9
A. Infectious & parasitic	2.8	4.7	2.4	0.6	0.4	1.5	2.6	5.5	18.0	0.7	0.4	7.0	4.2
B. Respiratory infections	9.2	4.8	2.9	1.3	0.9	2.4	9.6	5.9	3.1	2.0	1.2	2.7	2.6
C. Maternal conditions	-[a]	-	-	-	-	-	-	-	7.9	0.2	-	2.8	1.4
D. Perinatal conditions	11.0	-	-	-	-	0.8	11.7	-	-	-	-	0.8	0.8
II. *Noncommunicable*	67.0	70.1	75.2	92.5	94.2	84.4	67.9	75.4	65.4	94.4	92.3	81.0	82.7
A. Malignant neoplasms	1.6	5.6	5.3	17.6	18.1	11.9	1.4	6.0	4.6	18.9	12.6	9.9	10.9
B. Other neoplasm	-	-	-	-	-	-	-	-	-	-	-	-	-
C. Diabetes mellitus	-	-	0.8	1.8	0.7	0.9	-	-	0.8	2.9	0.9	1.1	1.0
D. Nutritional/endocrine	9.1	10.1	1.1	1.2	1.0	2.0	9.3	11.9	2.8	1.7	1.0	2.7	2.3
E. Neuropsychiatric	4.9	30.5	42.6	27.3	21.5	29.4	4.2	30.9	29.1	23.1	23.1	24.2	26.8
F. Sense organ	0.1	-	-	0.2	0.2	0.1	0.1	-	-	0.6	0.4	0.3	0.2
G. Cardiovascular diseases	1.9	1.6	6.7	17.6	33.0	16.9	1.7	1.6	2.8	11.1	36.6	16.9	16.9
H. Chronic respiratory diseases	2.0	12.6	3.7	3.7	6.3	4.7	1.7	13.1	3.4	3.4	3.8	3.7	4.2
I. Diseases of the digestive system	2.2	1.1	4.0	6.6	4.7	4.6	1.6	1.1	2.0	4.7	4.0	3.2	3.9
J. Diseases of the genito-urinary system	0.3	0.4	0.9	3.6	4.0	2.4	0.2	0.5	0.7	1.7	2.7	1.6	2.0
K. Skin disease	-	-	-	-	-	-	-	-	-	-	-	-	-
L. Diseases of the musculo-skeletal system	-	6.2	5.3	7.7	2.9	4.8	-	7.1	14.4	17.6	4.8	10.1	7.4
M. Congenital abnormalities	44.1	-	-	-	-	3.1	47.0	-	-	-	-	3.1	3.1
N. Oral health	0.5	2.0	4.8	5.1	1.8	3.5	0.5	3.1	4.9	8.4	2.5	4.2	3.9
III. *Injuries*	10.0	20.4	19.5	5.6	4.5	11.0	8.2	13.2	5.6	2.8	6.1	5.7	8.4
A. Unintentional	8.6	17.8	10.5	4.2	4.3	7.2	6.7	10.6	3.1	2.0	5.9	4.5	5.9
B. Intentional	1.4	2.5	9.0	1.3	0.2	3.7	1.5	2.6	2.5	0.8	0.1	1.2	2.5
Developing regions													
I. *Communicable, maternal and perinatal*	30.7	49.5	16.2	8.1	5.1	23.2	29.4	52.2	46.4	9.7	5.5	34.5	28.9
A. Infectious & parasitic	11.2	47.1	13.3	6.5	3.1	16.3	10.3	49.5	24.5	6.9	3.3	20.1	18.2
B. Respiratory infections	3.2	2.4	2.9	1.6	2.0	2.6	3.2	2.7	2.2	2.1	2.1	2.5	2.6
C. Maternal conditions	-	-	-	-	-	-	-	-	19.5	0.8	-	7.9	4.0
D. Perinatal conditions	16.3	-	-	-	-	4.3	16.0	-	-	-	-	4.0	4.1
II. *Noncommunicable*	57.1	31.7	53.6	83.9	90.6	59.1	57.8	32.6	46.6	86.0	89.5	56.4	57.7
A. Malignant neoplasms	0.4	2.1	2.4	9.6	5.5	3.1	0.8	0.8	1.9	9.6	4.2	2.5	2.8
B. Other neoplasm	-	-	-	-	-	-	-	-	-	-	-	-	-
C. Diabetes mellitus	-	-	0.3	1.3	0.4	0.3	-	-	0.2	1.8	0.5	0.3	0.3
D. Nutritional/endocrine	23.9	3.9	5.8	2.6	1.4	9.3	23.7	4.3	5.3	3.6	1.7	9.2	9.2
E. Neuropsychiatric	3.1	13.1	26.0	18.7	17.0	15.9	2.8	11.9	20.9	15.2	15.2	13.9	14.9
F. Sense organ	0.3	-	0.5	7.6	5.4	1.8	0.3	0.1	0.4	11.2	5.2	2.0	1.9
G. Cardiovascular diseases	1.5	1.7	4.3	16.8	35.0	8.3	1.0	2.6	3.3	16.7	36.7	7.9	8.1
H. Chronic respiratory diseases	4.6	5.8	3.8	4.5	12.5	5.4	4.8	5.2	2.9	5.8	10.7	4.9	5.2
I. Diseases of the digestive system	5.3	1.9	3.5	6.0	4.7	4.2	6.7	2.9	2.1	5.3	4.0	3.9	4.0
J. Diseases of the genito-urinary system	0.5	1.9	1.2	8.3	3.2	2.3	0.3	1.8	1.3	3.6	3.0	1.5	1.9
K. Skin disease	-	-	-	-	-	-	-	-	-	-	-	-	-
L. Diseases of the musculo-skeletal system	-	0.5	2.5	5.1	2.6	1.9	-	2.0	5.8	8.9	5.1	4.1	3.0
M. Congenital abnormalities	17.1	-	-	-	-	4.5	16.8	-	-	-	-	4.2	4.3
N. Oral health	0.4	0.8	3.3	3.3	2.8	2.1	0.4	0.9	2.5	4.3	3.1	2.0	2.0
III. *Injuries*	12.2	18.8	30.2	8.0	4.3	17.7	12.8	15.2	7.0	4.2	5.1	9.1	13.3
A. Unintentional	10.2	16.6	18.4	5.9	4.0	12.7	10.3	13.5	4.8	3.4	4.8	7.2	9.9
B. Intentional	2.0	2.2	11.8	2.1	0.3	5.1	2.4	1.7	2.2	0.9	0.2	1.8	3.4

[a] A dash represents less than 0.1%.

to treat a disease with a wider confidence interval as somewhat more important than the midpoint or expectation of the confidence interval. For all other conditions, the most reasonable approach, in the absence of other information, is to make decisions on the basis of the best estimate. In other words, we propose that for society as a whole the utility function of the magnitude of burden due to a particular disease is usually linear. Where wide confidence intervals appear to be concerned, investing resources in reducing the uncertainty around the estimates is also part of the optimal response.

One attempt to define the degree of uncertainty qualitatively for each estimate has already been initiated. Disease experts have been asked to grade estimates on a five-part quality-scoring scale. The reliability and validity of this quality-scoring system are still to be assessed. The results will ultimately be made available in the more detailed volume on the global burden of disease (*8*).

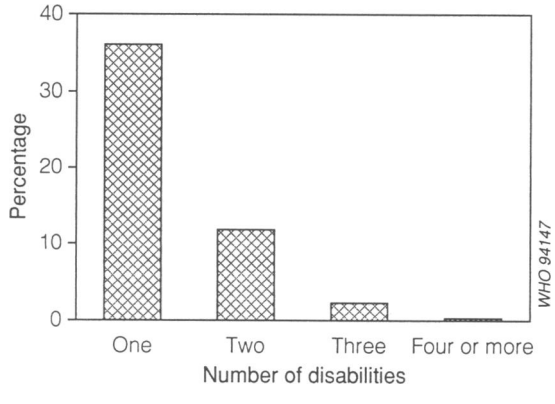
The total number of years lived with a disability is probably biased downwards because of omission of diseases and omission of idiopathic disabilities. More than 100 conditions were included in the study but many diseases have not been included. Disabilities from these missing diseases have been crudely estimated and included in the total. Deaths from residual categories of diseases not included in the GBD list have been estimated. Missing disabilities from these diseases causing mortality have been estimated by using the average relationship by Groups I, II and III between years lived with a disability and years of life lost due to premature mortality. But some conditions that lead only to disability and not to death may not have been covered by this procedure. Future work on expanding the number of conditions detailed in the GBD will eventually address most of this problem.

Perhaps of greater concern are the idiopathic disabilities where by definition there is no known cause. Take, for example, disabilities due to blindness. Blindness is included in the estimated burden through trachoma, onchocerciasis, glaucoma, cataract, congenital or perinatal factors, diabetes, neurological damage from malaria, and motor vehicle accidents and other trauma. Some idiopathic causes of blindness may not be included. (But for blindness the omissions are likely small.) In the future, cross-sectional datasets on the prevalence of certain impairments and disabilities could be used to assess the degree of omission of idiopathic outcomes.

While errors of omission may bias total YLD downwards, the problem of comorbidity biases the results upwards. The Global Burden of Disease estimates are built up from a disease perspective. Total disability in each disability severity class is just the sum of all disability incidence in that class across the 100 causes. Disability, however, afflicts individuals. The fact that individuals can have more than one disability of the same or different Classes at the same time cannot be ignored. When someone suffering a Class I disability gets a further disability the effect is not simply additive. Presumably several Class I disabilities may combine to raise someone's total disability severity to a higher Class. However, the effect of three distinct Class I disabilities will not be to triple the disability severity weight for the individual as is currently implied in the aggregation method.

Comorbidity will occur at random but may be exacerbated if having a disability means that one's probability of getting others is higher. A simple numerical example will illustrate the comorbidity effect, even if the probabilities of becoming disabled are all independent. Imagine a population where there are ten disabling conditions, each with an annual incidence rate of 1 per 1000 which is constant across all age groups. There is no remission or case-fatality for these ten disabilities. In the age group 60+, the prevalence of each disability is expected to be 6.8%. However, the total prevalence of individuals with one or more Class I disability is not 68% but only 50.6%. Fig. 5 shows the expected percentage of the population with one, two, three, or four or more disabilities. The net overestimation of YLD due to comorbidity even in this simple example depends on whether having two, three or more Class I disabilities moves one into a higher disability class. If two Class I disabilities moved one into Class II, but three or four was still Class II, then the overestimate of YLD would not be large since most of the comorbid effect is captured by those with two Class I disabilities.

Fig. 5. **Comorbidity: hypothetical distribution of population by number of disabilities.**



The magnitude of the overestimation of YLD due to comorbidity will be greater if the probabilities of getting different disabilities are dependent on each other. A diabetic has an increased risk of blindness, angina pectoris, amputation, neuropathy and renal failure. Household interview survey data suggest that there is considerable concentration of disability in an unlucky minority (*18–20*). At this stage of the measurement of disability, it is not feasible to take into account the interdependence of disability probabilities. Substantial further research is required to define a manageable method of accounting for these groups at high risk for disability.

Total YLD are not easily comparable estimates in the literature on the application of the ICIDH (*International classification of impairments, disabilities and handicaps*) to a population. In that work, disability is measured using a health expectancy: disability-free life expectancy. It would be desirable to use the wealth of data and expert estimates on the incidence and prevalence of disability by severity class and by age, sex and region to compute comparable health expectancy measures. For our DALY estimates to be directly comparable with the current publications (*17*), Class I, II and perhaps III disabilities would have to be ignored since their disability-free life expectancy ignores disability below some ill-defined threshold of moderate disability. Or one could define a hierarchy of health expectancies: disability-free life expectancy, life free of Class II or higher disability, life free of Class III or higher disability, and so on. Building a bridge between the sets of indicators will hopefully facilitate communication and sharing of information.

Traditionally, disability has been assessed in a cross-sectional fashion which defines the prevalence, by age and sex, of disabling conditions in a population. While this may be essential for determining the volume and nature of rehabilitation services, these data are of limited use for evaluating or monitoring primary or secondary prevention strategies. Cross-sectional surveys rarely provide insight into the causes of disability or indeed into the dynamics of the disabling process which often follows the occurrence of disease or injury. There is a clear need for monitoring systems which can identify new disabilities and then follow the evolution of these disabilities. Such systems will allow reliable retrospective assessment of the underlying cause of disabilities and will yield valuable prospective information on the nature, timing, and severity of subsequent complications and associated morbidities and the impact of interventions. If monitoring the burden of disease becomes a priority, then establishing cost-effective mechanisms to measure the burden of disability over a period of time will be critical.

Many countries in the Commonwealth of Independent States (CIS) already have in place monitoring systems for disability for determining eligibility for state benefits. These registries record all individuals with disabilities that interfere even partially with the capacity to work. Each disabled person is examined by a panel of physicians and social workers each year. For example, in Uzbekistan nearly half a million adults aged 18 to 60 years are registered with disabilities. Disabilities are classified according to severity and cause. Such detailed information on disabilities can be used both to validate the efforts to measure the National Burden of Disease in these countries and also to monitor trends in the burden of disability. By expanding such systems to the entire population, not just the age group 18 to 60, these systems in the CIS hold great promise for monitoring disability trends and causes. For other countries, a sample registration system for disability akin to the sample Registration Scheme for mortality in India or the Disease Surveillance Points system in China may provide a cost-effective alternative to complete registration of the disabled. Development of sample disability registration schemes should be a major theme for future research.

This study is a first attempt at quantifying a complex phenomenon in a way that can inform health policy debates. Six recommendations for future effort emerge. (1) Those conditions, which are estimated to cause many YLD and are the most uncertain, should be the focus of further epidemiological research. (2) Further work on the burden of disease should concentrate on improving the mapping from disease to impairment and then to disability. We hope that the publication of the results of the Global Burden of Disease study will install a new sensitivity to disability issues among some disease epidemiologists. (3) This sensitivity to disability issues should extend to better quantification of the cost-effectiveness of health interventions that prevent or treat disability. (4) Simple methods to adjust the results of the burden of disease exercises for comorbidity should be developed. (5) The number of conditions included in the Global Burden of Disease analysis should be expanded and the coverage of particular disabilities validated through cross-sectional work. (6) Methods for prospective monitoring of disability on a sample or general basis should be developed and applied.

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Résumé

La mesure quantitative de l'incapacité: données, méthodes, résultats

Une méthode destinée à remplacer les méthodes transversales d'évaluation de l'incapacité est exposée ici et ses résultats sont indiqués pour 1990. La méthode ne fournit pas d'estimation de la prévalence de l'incapacité, mais permet d'estimer le nombre de DALY (*disability-adjusted life years*: années de vie ajustées sur l'incapacité), supposées être vécues *ultérieurement*, d'après le profil estimé de l'incidence des maladies et des traumatismes survenus en 1990, puis en estimant la proportion de ces événements susceptibles de conduire à l'incapacité, la durée moyenne de ces incapacités et leur gravité comparée en termes de limitation de l'activité. Dans le présent article, ces DALY ont été désignées par YLD, de *years of life lived with disability*, ou années de vie vécues avec une incapacité, pour les distinguer de l'autre composante des DALY, à savoir celle qui résulte du décès prématuré. Les hypothèses, les méthodes et les modèles utilisés pour estimer les YLD sont indiqués en détail dans l'article. On y trouvera notamment la description du modèle de base de maladie utilisé dans cette étude (le Harvard incidence-prevalence model) montrant comment on peut obtenir les taux d'incidence, les durées, les taux de prévalence et de létalité de façon à garantir leur validité interne. Des exemples de résultats donnés par le modèle sont présentés, ainsi que la distribution de la gravité de l'incapacité concernant quelques maladies et traumatismes précis.

Dans la mesure où la base de données empirique utilisée pour estimer les paramètres nécessaires à l'estimation des YLD est extrêmement limitée, les estimations données dans cet article ont nécessairement des intervalles de confiance étendus. Elles indiquent néanmoins qu'à l'échelle mondiale, seul un quart environ de toutes les DALY de 1990 a pour origine une maladie transmissible ou une affection maternelle ou périnatale. Plus de 60% sont imputables aux maladies non transmissibles et environ 13% aux traumatismes. Par exemple, les maladies non transmissibles représentent plus de YLD en Inde que dans l'ensemble des pays industrialisés. Au fur et à mesure que les pays effectuent leur transition sanitaire, la répartition des YLD se déplace vers les maladies non transmissibles, ce qui correspond au profil observé de la mortalité.

Concernant les classes d'âge, un quart du nombre de YLD dans le monde est imputable aux maladies et aux traumatismes chez le jeune enfant. Toutefois, elles représentent chez le jeune adulte (15–44 ans) une part significativement supérieure (35%). Cette tendance se retrouve dans toutes les régions, donnant à penser que la protection et la promotion de la santé chez le jeune adulte est une priorité mondiale. Le taux de YLD tend à être plus grand chez les hommes que chez les femmes, à l'exception de la classe d'âge apte à la procréation pour ces dernières.

Les causes spécifiques majeures de YLD varient d'une région à l'autre; deux causes cependant, les affections psychiatriques et les traumatismes, occupent le devant du tableau partout dans le monde. Cette conclusion ne ressort pas clairement de l'analyse des causes de décès et il est donc urgent de mettre en œuvre des systèmes ciblés de surveillance de l'incapacité pour développer les connaissances concernant les séquelles invalidantes des maladies et des traumatismes, et pour ainsi disposer d'une meilleure information lorsqu'il s'agit des programmes de prévention de l'incapacité.

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